HOME AND COMMUNITY CARE SUPPORT SERVICES
North Simcoe Muskoka

Caregiver’s Support Guide

October 2021

Ontario

TABLE OF CONTENTS

ACKNOWLEDGEMENTS

The Caregiver's Support Guide has been an extraordinary effort.

The Family Alliance Service Team (FAST) Family-Centred Care for Adults with Disabilities and their caregivers first developed The Caregiver's Support Guide in response to requests for advice. Many questions and concerns surfaced during interviews between the FAST team, clients, and their caregivers. The plan was to compile and share some of the best material and resources.

The overwhelming response to The Caregiver's Support Guide led us to re-write the guide in a more generic way. We are grateful to the many people who reviewed and provided crucial input to add personal perspective.

Special recognition goes to Taking Care While Caregiving sponsored by Barrie Community Health Centre, resources from Alzheimer Society of Canada, Canadian Mental Health Association, Hospice Society, Caregiver's Alliance and most importantly, from caregivers who have shared their trials and suggestions. Also, the guide would not exist without the efforts of FAST team, Celia Tavares, BSc.OT, and Brenda Jenkins, MSW, RSW.

THANK YOU!

HOME AND COMMUNITY CARE SUPPORT SERVICES

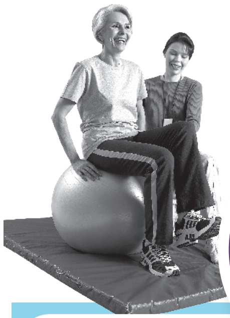
Home and Community Care Support Services North Simcoe Muskoka is funded and regulated by the Government of Ontario. Our mandate is to work with people of all ages - children, adults, seniors - as well as health system partners to help connect patients with a wide range of community-based health care resources.

Patient

Home and Community Care provides patients with information and access to qualified care providers and links patients to the many services available in North Simcoe Muskoka. Our staff seek to understand your personal situation, support you through the entire care journey and help you make informed decisions. We work hand-in-hand with the patient, their caregivers, and partners to develop a plan of care and arrange for the delivery of services that are right for them.

Care Coordinators

Care Coordinators assess and discuss your needs, develop your health care goals, connect you to community resources, and co-create a care plan with you for getting care at home, at a community clinic and/or through a community program close to you. Care Coordinators also help you access care in another setting where appropriate. These include, but are not limited to: Adult Day Programs, Assisted Living, Supportive Housing, Convalescent Care, Long-Term Care, and Residential Hospice. Care Coordinators will also provide information and education to support your independence, health, well-being, and safety.



Home and Community Care Services

We offer a wide range of community and home care services based on each individual's care needs. For example, services might include nursing, personal support, physiotherapy, occupational therapy or speech-language pathology.

Community Support and Programs

We are responsible for managing assessments, eligibility and waitlists for adult day, assisted living, and residential hospice services. Our team is also able to refer patients to private or publicly funded programs that may be purchased, or are covered under private insurance plans. Our Information and Referral team can connect patients to various community support service agencies, which can help with tasks such as housekeeping, snow removal or yard work.

Long-Term Care

We are the access point for ensuring long-term care is the right place for you, and for authorizing admission to Long-Term Care homes across Ontario. Your eligibility for entry into a Long-Term Care home will be assessed by one of our Care Coordinators who will work with you to complete your application.

HOW TO PREPARE YOURSELF FOR CAREGIVING FOR YOUR LOVED ONE

The most effective way to prepare yourself for the many responsibilities you will be faced with is to learn about:

- What the disease/condition is and how it will affect your loved one;
- How might you support your loved one;
- What services are available to help you;
- Who you can turn to with questions and concerns;
- What other sources of information you can use to learn about caregiving;

If you have a Power of Attorney or are the designated Substitute Decision Maker for the patient, also consider these questions:

- Do you have enough information about the person's medical condition?
- Do you know what the lasting effects of the illness will be?
- Do you know what changes may occur due to the illness/condition?

Ask to sit in on meetings with care providers about the care plan. This can be an excellent way to gain information on the person's progress and the treatment plans of the professionals involved. Caregivers need to fully understand the disease.

Read books or watch videos about caregiving.

Use support groups to get first-hand information and support from other caregivers.

- Become an expert on the situation.
- Educate yourself: find out what's available in your community.
- Become active: advocate for you and your loved one's rights.
- Speak with other caregivers. Do not wait to seek support as a last resort.
- Help is available to prevent Caregiver Burnout (see page 12).

THE PERSPECTIVE OF THE PERSON RECEIVING CARE

Like you, the person you are caring for is experiencing a wide range of emotions due to the changes and losses they are experiencing. In order to understand these emotions fully, you need to know what they may be.

As a normal adjustment to new health concerns, the person you are caring for may experience:

- A sense of losing control over their life because of their condition. In an attempt to try to maintain control, they may resist your attempts to care for them. This is a common reaction to the loss of independence;
- Sadness from a changed self-image;
- Fear of becoming dependent and a burden to the family;
- Fear that old friends will distance themselves;
- Anger and frustration towards their condition (which can at times be misdirected);
- Denial of the condition or its lasting effects; and
- Fear of becoming isolated from the world, since they may no longer be able to get around as easily as they once did.

With time and support, your loved one will adjust to their new situation. Encourage them to get involved in something outside the home such as a Day Program, support group, or leisure activity. This can provide an outlet for their emotions and can help them feel less alone and/or helpless.

DEALING WITH YOUR EMOTIONS

As a new caregiver, you may be experiencing a wide range of emotions. To get through this time of transition, it is important that you understand and deal with them effectively.

You may experience:

- Depression and resentment over loss of income, social activities, freedom, privacy, companionship, sexuality, and loss of your loved one's contributions
- Anger with the illness for forcing you into being a caregiver and impacting your plans
- Frustration with family and friends who may have conflicting ideas about what you should be doing
- Feeling isolated or uncertain about becoming a caregiver
- Guilt for feeling angry or resentful when you are healthy, while your loved one is ill, or for not living up to unrealistic expectations

You may feel:

- Good about the contribution that you are making
- Pride in all that you have accomplished
- Improved ability to reach out and be sensitive to someone else's needs
- New sense of strength in watching your family pull together
- Pleasure in maintaining your loved one's dignity and comfort
- Gratitude for the blessing of having developed a closer, more intimate relationship with the person you are caring for.

Caregiver feelings can be complicated and overwhelming. It's important that caregivers allow themselves to feel and express the full range of your emotions, and have an opportunity to express their feelings in a safe environment where they will not be judged. All feelings are valid. Only by acknowledging and expressing feelings openly can we begin to deal with them.

Here's suggestions to help caregivers deal with their emotions:

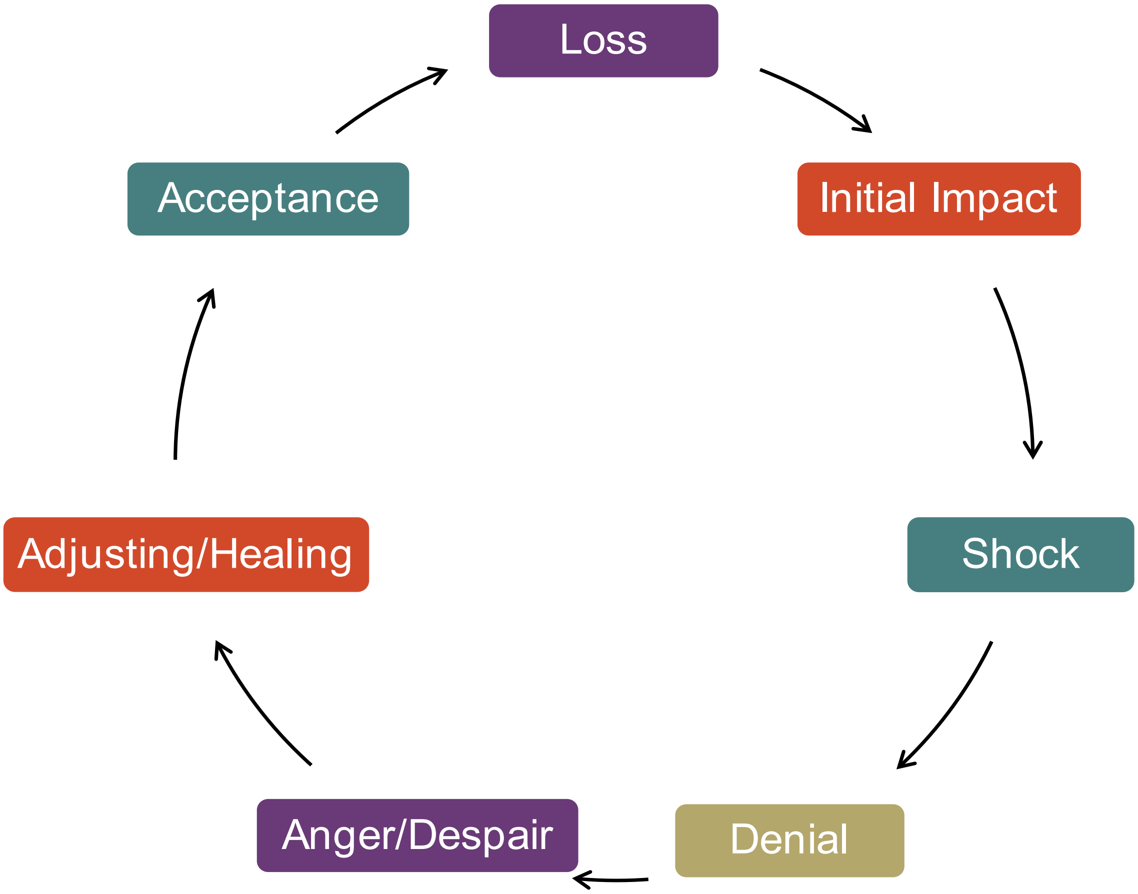
1. Accept your emotions for what they are.
2. Find support that works for you:
    a. Talk to your Care Coordinator, therapist, social worker, or physician
    b. Talk to friends, family, another caregiver, or spiritual advisor
    c . Get help from community resources (see page 21)
3. Be open to expressing your feelings in other ways - paint, sing, cry, laugh, write, pray, exercise. Release your feelings however best suits you.

THE GROWTH CYCLE – HEALING

You and the person you are caring for may be experiencing many changes because of the health concerns they are facing. Some of these losses you share, while others are specific to each of you.

Working through your emotions is a very individual process that takes time. To understand each other’s moods and behaviours, it is important to realize where each of you are on the cycle of emotions shown below.

This cycle represents a normal and healthy range of emotions that people go through when they experience any form of loss.



- You and the person you are caring for may not be at the same stage of this cycle.
- More than one emotion may be experienced at a time.
- The speed at which you move from one stage to the next is different for everyone.
- These stages do not always follow each other in order, and it is common to move back and forth between stages.

CARING FOR A PARTNER

Caring for a partner can be hard on any relationship. You may be coping with loss of companionship, wage-earning, sexual contact, and future plans. At the same time, you may feel less important since all the attention is focused on your partner and the full responsibility for managing the household, child care and finances now lies squarely on your shoulders.

What can you do to cope?

Accept help from family, friends, and professionals so that you can take a break. This will give you more time to talk and do things that are not related to caregiving. Allow yourself to feel all of your emotions, the good ones and the difficult ones, and share these with each other. Understanding what it is like for the other person will open lines of communication.

Caregiving does not mean parenting. Encourage your loved one to continue to do as much for themselves as possible. This will result in increased confidence, feelings of self-worth, and an improved sense of control over their environment. It will also decrease the number of tasks you must do.

Seek counselling if you are having difficulty resolving your concerns. It may assist both of you to effectively deal with your emotions and concerns. Ask your family doctor for a referral to a counselling agency or counsellor.

Role imbalance

In many relationships, two people share responsibilities. If one half of the team is down, the other half must pick-up those responsibilities – in addition to caring for an ill person. For some, the new or added responsibilities are related mostly to household chores. For others, shouldering all the financial responsibilities is the greater challenge. This can be very overwhelming, especially if you also have job demands or your own health problems.

The key is *do not try to do it all by yourself*. Accept help – seek support! Both of you will experience a period of adjustment. Adding caregiving duties to your role will have an obvious impact on your relationship. Allow your partner to offer you support from time to time. It will give them pleasure to know that they have been able to help or comfort you, and will allow more balance in your relationship.

CARING FOR A PARENT

Many people want to maintain their independence in their own home for as long as they can. When parents become less able to take care of themselves, family members are faced with coordinating and providing hands-on care and support.

Recognize denial, stubbornness, and complaining as defensive reactions to the changes and losses your parent is experiencing, and not the care they are receiving. Learn not to react to the behaviours, but the reason behind them.

Regardless of who provides care, resentment can arise between siblings when the primary caregiver does not feel they receive enough support from other family members. Many of these caregivers can feel angry, abandoned and unappreciated by their family.

Why is the responsibility sometimes left to one person?

- A parent may only want one particular child to care for them.
- Family members who contribute financially may feel they have given enough.
- You may not be assertive enough in demanding help from other members of the family.
- You may be unwilling to give up control and share the task even when exhausted by it.
- Family members who live far away are unable to help with daily caregiving tasks.
- Some family members refuse to cooperate, or ignore the situation altogether.
- Siblings who work outside the home may feel that the family member who does not is the only one with enough free time to assume the burden.
- Some people may hold the old-fashioned belief that caregiving is a female's responsibility (Carter, 1994).
- Family members who have young children may feel that those without children have more time to provide care.
- Most medical teams request one person be appointed as the primary contact.

What can you do to cope?

- Communicate your parent's progress to your family frequently. Explain to them, and your parent, the things you may be experiencing difficulty with and why.
- Develop a plan that shares parental care with more than one person.
- If you feel unable to arrange these discussions because you are too upset or exhausted, speak with your Care Coordinator; they can help you with this.

DEALING WITH ISOLATION

Do you feel:

- That you have no one to talk to, to support you, or give you advice?
- Like you're so busy taking care of your loved one's needs that you have no time to even share a cup of coffee with a friend?
- That old friends have pulled away from you?
- Everyone always asks how your loved one is, but never asks how you are doing?
- Like you are imprisoned in your own home?
- That only those who have been a caregiver before can truly understand what you are experiencing?

If you have answered yes to any of the questions above, then you may be physically or emotionally isolated. This is a very common and serious concern, and it can lead to feelings of anger and/or depression.

Caregivers need support!

You can gain support by connecting with other caregivers through support groups or by having a telephone buddy. Sharing your experiences with others is the best way to fight the feeling that you are the only person in the world with these problems. Having someone to share with can significantly improve your ability to cope with your responsibilities and feel supported.

Peer support can be an excellent way to:

- Learn about your loved one's condition;
- Alleviate your loneliness;
- Give you an opportunity to focus on yourself;
- Brainstorm solutions to your problems;
- Relieve stress;
- Give you hope as you listen to how others have coped in similar situations;
- Give you the opportunity to laugh about your circumstances with others who understand and are not judgmental;
- Gain firsthand information about community resources, professional help, and the latest equipment;
- Give you the opportunity to cry or talk with someone who understands that you have your own needs, and therefore will not make you feel guilty about your feelings; and
- Give you the opportunity to help another with your suggestions and ideas.

PREVENTING CAREGIVER BURNOUT

At first, most caregivers go through a “honeymoon” phase where they accept this new role with a sense of idealism, hope, and eagerness to do well. As time goes on, fatigue may set in, disappointments and frustrations may arise, and you may start to feel the effects of burnout.

Burnout is a sense of being completely overwhelmed and unrewarded (Carter, 1994). It is a common feeling among caregivers that can have negative consequences if it is not addressed quickly.

This can be dangerous to you and your loved one. Feeling stressed over long periods of time can affect your health, motivation, attitude, mood, and ability to cope with daily responsibilities. Burnout can be avoided and is not permanent.

What creates burnout?

- High expectations of yourself and others.
- Strong or unrealistic dedication to making things ideal for your loved one.
- Difficulty saying no and/or difficulty asking for or accepting help.
- Consistently sacrificing yourself and your needs for the benefit of others.
- Feeling as though you are the only person capable of providing care.

How do you avoid burnout?

- Acknowledge your new roles and responsibilities.
- Be able to recognize the symptoms of burnout.
- Pay more attention to yourself.

Common physical symptoms of burnout include …

- Being unable to sleep well.
- Headaches and backaches.
- Feeling tired most of the time – physically drained.
- Changes in your weight.
- Lingering colds.

Common emotional symptoms of burnout include …

- Being easily irritated and frustrated.
- Feeling anger and resentment.
- Feeling sad, lonely, overwhelmed or overloaded
- Decreased self-esteem
- Depression

What are other things that you can do?

1. Focus on your loved one’s strengths. Encourage them to do more for themselves, and acknowledge their efforts. This will increase their self-confidence, lessen resentment of being dependent on you, and decrease the number of tasks you have to do.

2. Let go. One person can’t do it alone. You are human and you have limitations. It is okay to say no to increasing demands. It is rarely true that you're the only one who can provide care. Ask for help from friends, family, and community services. Accept help. Don’t wait for your own health, emotions, or relationships to suffer.

Consider these questions to help you identify your needs:

- What do I need help with? (e.g. bathing my loved one, transportation, etc.)
- When and how often do I need this help (e.g. once per week)
- Who will I ask to help me with each task? (list who you will ask first, and then second if your first choice is not available)
- When will I make the call to ask for this help? (e.g. this morning)

As you come to understand and accept the ways you cannot and should not help, you allow yourself to do what is uniquely yours to do.

3. Prioritize tasks and learn to manage your time. Schedule tasks throughout the day/week, including breaks and private time for yourself.

Define your limits about what you are prepared and able to do. This will help you see more clearly what is needed and what is realistic for you to provide.

4.Take advantage of respite care. Respite care is when a friend, volunteer, family member, or a professional takes care of your loved one while you take a break for a few hours or a few days. Ask your Care Coordinator about respite care options.

Respite is important for you as a caregiver to regain strength and allow you to be healthier and better able to cope with your responsibilities.
Examples of respite services include Adult Day Programs, Homemaking Services, Friendly Visitors, temporary stay in a Long-Term Care Home, and Hospice Services.

5. Use your caregiving team to help solve problems. Learn to trust them; they are there to support you.

Appreciate your own efforts.

Draw strength and comfort from the dignity, care, and love you have provided and remember that it is not your responsibility to fix it all.

6. Maintain a life outside of your home. Insist on time for yourself – you deserve it!
7. Keep a good sense of humour.
8. Find strength in your religion/faith. This can be an excellent source of inspiration.

PREVENTING CAREGIVER BURNOUT

In some circumstances, caregivers may be under such extreme stress that they may put themselves at risk for mistreating or neglecting their loved one. In most instances, this behaviour is not intentional, but it can have many undesirable consequences.

Stress can result from many different things - and be experienced in different ways - including exhaustion, frustration, guilt, resentfulness, sadness, etc. Having a productive outlet to release or vent these feelings is healthy - such as exercise, art, or by talking with friends or professionals.

Venting becomes inappropriate when the care receiver becomes the target of the venting and is not in a position to help alleviate the situation. Abusive situations may arise if the caregiver feels justified in continuing this behaviour, or does not seek outside support.

Caregivers may experience extreme stress when there is:

- Depletion of resources (money and support for physical, mental, emotional health)
- Unrealistic expectations, caregiver feels overwhelmed trying to achieve these expectations
- Caregiver feels frustration, resentment, and sometimes anger

What is the definition of abuse/neglect?

Abuse is the misuse of power or the betrayal of trust or respect of an individual which can sometimes result in physical or emotional harm. Abuse or neglect of a person can be unintentional, such as the actions of a stressed but caring spouse, or an act of omission such as inadvertently failing to provide the necessities of life.

Denial of a vulnerable person's fundamental rights is also considered abuse; for example, withholding information, denial of privacy, denial of visitors, restrictions of liberty, denial of independent legal advice, or mail censorship (Protocols for Abuse of the Vulnerable Adult, Simcoe York District Health Council, February, 1999).

Who are potential abusers?

Friends, spouses, children, hired homemakers, landlords, or caregivers …
anyone who has some control or power over the individual's care and well-being.

What are the types of abuse that care receivers may fall victim to?

- **Physical abuse** – pushing, shaking, hitting, withholding or over-medicating, using restraints, or any other treatment causing injury or physical discomfort. Signs to watch for include unexplained injuries, depression, and obvious changes in behaviour (sleeping a lot).

- **Financial exploitation** – dishonest use of a vulnerable person's money or assets, misuse of Power of Attorney, theft, selling of property/valuables, fraud, withholding money, etc. Signs to watch for include unexplained disappearing possessions and difference between income and standard of living.

- **Psychological or emotional abuse** – any behaviour which disrespects and diminishes dignity and self-worth, such as humiliation, withholding affection, treating adults like children, threats or intimidation, manipulation, etc. Signs to watch for include being socially withdrawn, decreased self-esteem, appears nervous when abuser is around, care receiver may feel unable to exert control over situations.

- **Neglect** – denial of basic necessities of life (food, shelter, and clean/appropriate clothes for the season), denial of medical attention, denial of contact, abandonment, leaving an individual in unsafe or isolated places. Signs to watch for include weight loss, confusion, pressure sores, dirty clothes/environment, unkempt appearance, poor health, and loneliness.

(Taken in part from Protocols for Abuse of the Vulnerable Adult, Simcoe York District Health Council, February, 1999.)

When is the caregiver most at risk for abusing or neglecting a loved one?

- When the care receiver's capabilities have diminished, resulting in increased burden on the caregiver;
- When there is a lack of support for the caregiver or knowledge of community resources;
- When the caregiver has many other demands/commitments placed upon them;
- When the caregiver has never had a very good relationship with the care receiver.

(Taken in part from Elder Abuse brochure, Ontario Network for the Prevention of Elder Abuse.)

What can you do to prevent yourself from venting your feelings of stress on your loved one?

The best way to avoid unintentionally venting your stress on your loved one is to prevent day-to-day responsibilities or stresses from building up to the point that they are overwhelming you. This requires that you be honest with yourself about what you are realistically able to manage, that you inform yourself about community resources and services that can support you, and that you take care of yourself.

If you don't live with your loved one, what can you do to help protect them from becoming a victim of abuse?

As a caregiver, you may not be living in the same place of residence as your loved one. In this case, you are required to manage their care from afar, which can offer some unique challenges.

Some of these challenges and suggestions for coping with them are outlined in *Being a Long Distance Caregiver* (on page 16). In these circumstances, your loved one will be receiving most of their direct care from one or several other persons.

If you suspect that someone is mistreating your loved one, don't hesitate to take action. It is not necessary to have proof of mistreatment before seeking help. Report your concerns to the police so that a counsellor may try to resolve the abusive situation. If you suspect that a staff member, visitor, or other resident is mistreating a resident of a nursing home, you are required by law to report it to the Ontario Ministry of Health. Your report will remain confidential.

To report a complaint, call the Long-Term Care ACTION Line:

Toll free: 1-866-434-0144
Hours of operation: 8:30 a.m. to 7 p.m., 7 days a week

You can take the following steps to protect your loved one from falling victim to mistreatment:

- Stay informed about the care your loved one is receiving, who they are receiving it from, and when they are receiving it;
- Stay involved – communicate often with your loved one, visit regularly;
- Know the signs to watch for;
- Suggest that your loved one not keep valuable jewelry or large amounts of money in the house;
- Warn your loved one not to sign any documents they do not fully understand;
- Arrange for automatic deposit of pension cheques and withdrawal for payment of monthly bills; and
- Instruct your loved one to never give personal information to someone they do not know.

(Taken in part from *Let's Break the Silence* brochure, Information Orillia.)

BEING A LONG DISTANCE CAREGIVER

Family members may live far apart. Long distance caregivers may face:

- Travel costs and long distance phone bills
- Difficulty exchanging information
- Feelings of guilt or anxiety about not being your loved one more often
- Difficulty traveling frequently due to other family responsibilities or job demands

What you can do to cope:

1. Get information and support from your Care Coordinator to help you coordinate care. Attention to detail is critical to successful long distance caregiving.

2. Plan for emergencies to reduce anxiety. Leave a key to your loved one's home with a friend or neighbour for quick and easy access in case of an emergency.

3. Consider an "emergency response system" so your loved one can contact emergency attention at the touch of a button. For further information, contact your Care Coordinator.

4. Consult with your Care Coordinator regularly to discuss concerns and assist with relaying information to the other professionals involved. Your Care Coordinator can also help you learn about community and private services.

5. Attend care provider meetings whenever possible to meet the care providers, to discuss their roles and be brought up-to-date on your loved one's progress. Usually the Care Coordinator arranges these meetings.

6. Use a "Communication Book" where all care providers can note concerns or questions for you. You can use this as a way to update yourself on the week's events and communicate back to the care providers.

7. Prioritize tasks that you want to accomplish with each visit. Keep a list of people to talk to and things to do. This will help you stay focused and avoid confusion.

8. Make sure all care providers know how and where to reach you. Leave your name and phone number with people who may not be directly involved (e.g. the bank manager.)

9. In some cases, the condition of your loved one may lead you to move in with them, or to move closer to them to provide care. This may be a temporary or permanent arrangement. In other cases, some people decide that their loved one needs to move in with the caregiver. Whatever the arrangement, prepare yourself for this significant transition (e.g. loss of privacy, less control, and change in routines.)

BEING A CAREGIVER IN A RURAL SETTING

Caregiving in the country may be a challenge. Due to smaller populations, the use of services in rural communities is often less than in city centres. As one rural caregiver said, “Don’t isolate yourself more than the situation already does.”

What can you do to cope?

1. Talk to your Care Coordinator about what services are available in your community. Options might include nursing, personal support, therapy, meal delivery, foot care, hair care, or other supports.

2. Check with your church, community centre, or local service clubs to learn about volunteer and support services.

3. Stay in touch with friends and neighbours, even if you can only manage it for brief periods. Talking to others may help you to feel less alone and cope better.

4. Get out to community events as often as you can. Both you and your loved one (if they are well enough to go with you) will benefit from socializing and the change of scene.

5. Talk with your therapist or Care Coordinator about linking up with another person who has gone through a similar experience. Having a telephone buddy can be an excellent way to avoid lonliness.

MANAGING CARE AT HOME

In addition to therapy, nursing and placement coordination services, Home and Community Care Support Services may also provide personal support services to families who require assistance with day-to-day care of their loved ones.

Your Care Coordinator will discuss your need for personal support services to help you identify how the personal support worker can best assist you.

Personal support workers can help with:

- Personal care (e.g. dressing, feeding, toileting, bathing, and transfers)
- Essential housekeeping (e.g. cleaning that maintains a safe environment, laundry, meal preparation, and personal errands) which frees up your time and allows you to provide personal care

If it is determined by you and your Care Coordinator that this is required, a personal support worker may be able to assist with things such as running the household or supervising your loved one while you participate in another task.

Personal support services can be started in the home consultation with your Care Coordinator. They may be at varying times of the day, or days of the week. You will have input as to how this service can best fit your needs.

In case of terminal illness, where there is a strong desire to remain at home or when the care needs become complex, you will need to work closely with your Care Coordinator as they can help access more help (private insurance benefits, resources such as hospice, or private pay care).

There are some situations where care needs are so complex and available resources are just not enough to meet the needs, and your loved one will require admission to a hospital or hospice facility.

DEVELOPING A CRISIS PLAN

A crisis plan is a back-up plan that takes effect if you are unable to care for your loved one. It may be needed because:

- You become ill
- Other responsibilities demand your attention
- You need a break from your caregiving obligations
- There is a personal emergency
- You are having difficulty managing needs
- You are unable to get to the care receiver due to unforeseen circumstances (such as bad weather or car trouble)

Your back-up plan will help you think about what you can do when unexpected situations arise. A well thought-out plan will help to decrease your stress and anxiety during a crisis and identify who your supports are and how they can be reached. It will also allow you to consider details you may not have time to think about later.

Develop your plan (below) with your loved one and discuss it with your emergency contacts and supports.

My Crisis Plan

Name of Family Doctor:____

Name of Care Coordinator: ______________________________________

Back-Up Emergency Contact:

- Name:____
- Relationship: ____
- Phone number: ____

Important facts that my key supports need to know:

____

____

____

Date to review and update plan with key supports: ________________________

FINANCIAL CHALLENGES

Because of your loved one's health issues, there may have been a loss of income. You may also have needed to reduce your hours at work to be a caregiver. As well, health situations can result in increased medical costs.

Managing your financial resources at this time can become more critical. It may even be a new experience for you. There are a few things you should consider as you take on this task. Ask yourself:

- What are my current sources of income?
- Is my loved one eligible for Canada Pension Plan (CPP), Disability Pension, and/or Family Benefits?
- Am I familiar with the full coverage of extended work benefits, group benefits plan, or private insurance?
- Am I aware of all the banking information that I will need such as account numbers, investment information, safety deposit boxes, and what the monthly payments are?

As a way to assist families, there are sources of funding you may be eligible to receive for items such as special equipment, medical supplies, and home modifications. Talk to your therapist or Care Coordinator for information.

Each funding agency has its own eligibility criteria and application procedures. Possible funding sources for assistive equipment and/or home renovation supports are:

- Assistive Devices Program (ADP)
- Canadian Paraplegic Association (CPA)
- Churches
- CMHC – Housing Assistance for Seniors' Independence (HASI)
- CMHC – Residential Rehabilitation Assistance Program (RRAP)
- Community Service Clubs
- Department of Veterans Affairs (DVA)
- March of Dimes
- Multiple Sclerosis (MS) Society
- Municipal Social Services
- Muscular Dystrophy (MD) Association
- Ontario Disability Support Program (ODSP)
- Personal saving and bank loans
- Trillium Drug Plan
- War Amps

You may also want to ask an accountant what tax benefits you are eligible for and what receipts to save.

THINGS FAMILY & FRIENDS CAN DO FOR YOU:

- Listening is the most important thing anyone can do for a caregiver.
- Giving caregivers a break by offering to stay with their loved one.
- Invite you to go out.
- Offer specific help, such as shopping, yard work, or banking.
- Don’t give advice unless it is asked for.
- Be supportive of the decisions caregivers make.

(Povided by the *Caregiver’s Voice* in Bracebridge, Ontario)

COMMUNITY RESOURCES

There are many community services available to help with different parts of your life. Here is a list of the types of services/resources that may be available in your community. Knowing what kinds of services are available can ease the confusion and frustration many people experience.

- Financial assistance
- In-home foot care, or hair care
- In-home nursing services
- In-home therapy services (e.g., occupational therapy, physiotherapy, social work, speech/language therapy, dietary services)
- Legal assistance
- Meal preparation
- Outdoor home maintenance
- Personal support services
- Prescription of special equipment (e.g., wheelchairs, stair lifts, walkers)
- Recreational facilities
- Respite
- Social clubs
- Information and support groups from organizations related to a disease group (e.g., Alzheimer’s, cancer, multiple sclerosis, stroke)
- Transportation
- Volunteer services

For information and referral to other community services:

- Call - 310-2222
- Visit - www.nsmhealthline.ca

10 TIMELY TIPS FOR CAREGIVERS

1. Get help with tasks and chores early on in the illness – your loved one will get used to having other people around the home.

2. Involve other members of your family from the beginning of the illness. Even if you are the only one who sees changes taking place, pass these on as information only, not as a debating issue.

3. Access all the information you can about the illness and learn as much as possible about its progression – source of information include your doctor, disease-specific organizations, and your local library.

4. Recognize and learn to accept that anger, anxiety, and guilt are normal feelings given the situation you are experiencing – they come not only from being tired, but also from the losses you are experiencing.

5. Join a support group as soon as you can. You do not need to be alone in this journey.

6. Every change in your loved one means more adaptation and change for you – acknowledge that this gives you the right to feel off-balance some days.

7. Forgive yourself for not being perfect. Caring for someone with a chronic or terminal illness turns your life inside out.

8. Connect with your family physician; ask for time to speak with them alone if you need to do so.

9. Get regular physical check-ups, eat a balanced diet and try to take time out to express your feelings. Accept yourself for being human and try to do at least one thing that you enjoy every day.

10. Take it one day at a time while planning for the future. Good planning means thinking about financial considerations, facility placement issues, or palliative care. BE KIND TO YOURSELF.

By Dorothy Orr, Caregiver Coach (re: dementia),
and adapted for all family caregivers by the Family Caregivers' Network Society.

ACKNOWLEDGEMENTS

The *Caregiver's Support Guide* has been an extraordinary effort.

The Family Alliance Service Team (FAST) Family-Centred Care for Adults with Disabilities and their caregivers first developed *The Caregiver's Support Guide* in response to a growing need for advice. Many questions and concerns surfaced during interviews between the FAST team, clients, and their caregivers.

The plan was to pull together some of the best material and resources under one cover and provide it to families and caregivers.

The overwhelming response to *The Caregiver's Support Guide* from Simcoe County and beyond, led us to re-write the guide in a more generic way. We are grateful to the many people who reviewed and provided crucial input into the many drafts, giving us a personal view of the contents.

Special recognition goes out to resources such as *Taking Care While Caregiving* sponsored by Barrie Community Health Centre, resources from Alzheimer Society of Canada, Canadian Mental Health Association, Hospice Society, Caregiver's Alliance and most importantly, from caregivers who have shared their trials and suggestions.

The guide would not exist without the efforts of members of the FAST team, Celia Tavares, BSc.OT, and Brenda Jenkins, MSW, RSW.

NOTES

Home and Community Care Support Services
North Simcoe Muskoka

Telephone: 705-721-8010
Toll Free: 1-888-721-2222

15 Sperling Drive, Suite 100
Barrie, ON L4M 6K9

www.healthcareathome.ca

To locate health service resources in North Simcoe Muskoka,
call 310-2222 (no area code required)
or visit

nsmhealthline.ca